Health Equity Data Analytics

Policy Recommendations Report: September 2020

Prepared for Connecticut Office of Health Strategy (OHS), Health Information Alliance (dba Connie), and UCONN Analytics and Information Management Solutions (AIMS)

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About the Project

The Health Equity Data Analytics (HEDA) team, comprised of Health Equity Solutions, DataHaven, and the Equity Research Innovation Center at Yale School of Medicine, was contracted by the Connecticut Office of Health Strategy (OHS) in 2018 to analyze how to embed health equity into the data architecture of a new health information exchange (HIE).

The Health Information Alliance (HIA), now doing business as Connie, was formed under the guidance of OHS to stand up, implement and manage the state's HIE. Meanwhile, UCONN Analytics and Information Management Solutions (AIMS) was contracted to design a statewide "Core Data Analytics Solution" (CDAS), including the development and implementation of electronic clinical quality measures (eCQM), to support healthcare quality improvement activities and value-based purchasing models.

In June 2019, the HEDA team published a 19-page report for OHS about this multi-phase project, including a discussion and literature review of the role of HIEs in promoting health equity, a national and statewide landscape analysis of how HIEs are envisioned to address health equity, and an initial set of recommendations of 2-3 health equity data elements that Connecticut could strive to incorporate into its HIE. These recommended data elements included high-quality and accessible information on race, ethnicity, insurance status, and geocoded residential address.¹

Perhaps now more than ever, it is clear that racism, discrimination, and socioeconomic conditions drive disparities in health outcomes in Connecticut, including COVID-19.² These conditions cannot be fully understood or addressed unless they are measured and utilized in ways that inform health care and public decision-making processes.

As stated in our June 2019 report, the supporters of this project, notably the Connecticut Office of Health Strategy and the Connecticut Health Foundation, recognize the need for timely, accurate data to drive improvements within the healthcare system. Connie can help health care providers and other decision makers obtain a comprehensive picture of their patients, potentially leading to better care and fewer unnecessary tests, while also creating opportunities to improve population health and reduce racial, ethnic, gender, and geographic health inequities.

¹ Abraham, M., Everette, T., McGann, S., Rizzo, T., Wang, K. Health Equity Data Analytics. June 2019. Report prepared for Connecticut Office of Health Strategy.

² For a discussion of these factors, see Davila, K., Abraham, M., and Seaberry, C. 2020. Towards Health Equity in Connecticut: The Role of Social Inequality and the Impact of COVID-19. New Haven, CT: DataHaven. See also Community-Level Factors Associated with Racial and Ethnic Disparities In COVID-19 Rates in Massachusetts. Health Affairs, August 27, 2020. https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2020.01040.

Overview of Continuing Activities

Following the publication of the report described above, the HEDA team has continued to identify key areas for consideration as the state advances the foundation of health equity in its HIE.

Use Stories Summary

In 2019, the HEDA team developed a range of user stories that describe ways that stakeholders believe health equity data could be used to improve health within Connecticut. These user stories identify the value propositions of specific analytic capabilities of health equity data elements that would facilitate key end users (e.g. health systems, providers, policymakers and state officials, community-based organizations, and healthcare consumers) in supporting opportunities of Connecticut residents to attain their optimal health and well-being.

The HEDA team identified the following high-value user stories that integrate race and ethnicity, geocoded residential address, and insurance status. For more information, refer to the HEDA team's User Story Report, which details use cases specific to various end users.

- All Payer Claims Database (APCD) Analytics
- Virtual Health Record
- Health Equity Dashboard
- Health Enhancement Communities
- Environmental Health Dashboard

Stakeholder Outreach Summary

Additionally, recognizing that healthcare systems are not the only entities collecting data nor the only organizations involved in leveraging data to support the health of Connecticut residents, the HEDA team conducted stakeholder interviews with community-based organizations and state agencies identified by OHS:

- Connecticut Community Cares
- Hispanic Health Council
- Thames Valley Council for Community Action
- CT Department of Housing
- CT Department of Mental Health & Addiction Services
- CT Department of Public Health
- CT Department of Social Services

Stakeholders were engaged in exploratory conversations about their collection of health equity data elements, as defined above. The objective of these discussions was to gain a preliminary understanding of what data sources exist outside of the electronic health record (EHR) that have health equity data and to discuss perceived opportunities and barriers to participating in the CT HIE. See Appendix A for summary tables. These discussions will inform future work, including but not limited to the technical assistance, that OHS will be offering to adopters of the HIE.

In 2019 and 2020, the HEDA team worked with UCONN AIMS to explore a limited data set that was available to the HIE at that time and reviewed additional data informatics literature. The sum of the activities described above inform the recommendations provided in this report.

Data Findings and Recommendations

In this section, we present strategies to help ensure that the approach to data lifecycle within the health information exchange (HIE) contains a robust foundation for advancing health equity.

In particular, it is important to understand the completeness and quality of existing and future data entering the HIE and work strategically to improve their utility. The HEDA team met several times with UCONN AIMS for demonstrations of the limited data set of commercial insurance from the all payer claims database (APCD). These data demonstrations suggested varying levels of quality and completeness for data related to the health equity data elements recommended by the HEDA team in their report submitted to OHS in June 2019 (race, ethnicity, insurance status, and geocoded residential address). Insufficient data on these elements will limit their value to advancing health equity in Connecticut.

To ensure the completeness and quality of existing and future data entering the HIE, we suggest implementing a process for understanding and assessing existing and future data elements. The suggestions below are grounded in the mission of the health information exchange as a mechanism to advance health equity. These recommendations focus around the initial targeted health equity data elements, including race/ethnicity, insurance status, and residential address. However, we recognize that there are other critical data elements that inform health equity and the process of including these other data will require additional strategies to optimize their usefulness.

Data Completeness

The Connecticut Information Exchange (Connie) is structured to ingest claims data from the APCD and clinical data from other sources including clinical providers, health systems and community-based organizations.

In order to conduct granular-level analytics based on race, ethnicity, insurance status, or area of residence, a minimum viable sample of data within a population of interest would be needed.

The APCD currently holds large insurance claims datasets that include these critical health equity data elements. However, knowledge of the completeness and accuracy of these health equity data elements is limited for commercial data, and not publicly available for Medicaid data. The HEDA team is not able to assess the overall completeness or accuracy of health equity elements captured in clinical data at this phase of implementation.

A clear baseline is the foundation for future policy efforts to ensure accountability for data quality. For example, from 2012-2018 there were 1.4M unique individuals who had commercial insurance. On average, approximately 9% of these individuals had a primary race listed and 6% had a secondary race listed. Approximately 10% of individuals had a primary ethnicity listed. Over time, the capture of primary race data has increased. In 2012, the primary race field was approximately 8% listed compared to approximately 9% in 2017. Primary ethnicity data decreased over time with over 10% listed in 2012 and under 10% listed in 2017. On average, secondary race data also experienced a marked decrease, with approximately 8% being listed in 2012 compared to less than 4% listed in 2017.³ Further investigation is needed to fully understand the data trends.

Due to the nature of this project, it was not possible to determine the extent of data on insurance or location status, although many elements (such as zip code) may be partially available. The HIE will likely hold other datasets in the near future, and incomplete health equity data elements are likely to be found in these other datasets as well.

HEDA Data Completeness Recommendations

- 1. Assess, track, and publicly report the existing baseline completeness and accuracy of each health equity data element in the APCD, and then in Medicaid and other available datasets.
- 2. Stratify this reporting by insurance providers, for clinical data by organization, by demographic group, and for other groups as necessary to create relevant baseline information.
- 3. Where major data limitations are known, prioritize and begin to understand them by investigating and documenting the reasons why data may be incomplete in the private claims datasets. This is important for accuracy and transparency. In particular, it is important for data providers and users to understand why data elements may be included in some instances but not others. Information bias may impact future analyses if data are included for certain groups more than others. The potential biases already introduced by data collection mechanisms (e.g. differences across datasets that relate to ICD coding or methods in which race/ethnicity,

³ CT APCD Limited Data Set (2012 – 2018). Released by CT OHS to UCONN AIMS. Commercial Population Analysis by: UCONN AIMS (2020).

address, and other data elements are captured) must be documented in the development and use of the HIE in a transparent way.

4. Develop more systematic processes to periodically investigate the completeness of health equity data elements as new or updated datasets are obtained by the HIE.

Other Considerations

• There are individuals living in Connecticut who may have a limited "data footprint" (i.e. uninsured, partial-insurance longitudinally, homeless). For these individuals, the state could develop a more comprehensive strategy to assess the health of those who may have a limited data footprint within the existing datasets. Techniques could include determining if there are mechanisms to analyze the populations that fall under the hospital's uncompensated care recording systems.

Data Quality

With large data systems, data inaccuracies are inevitable. These issues might stem from processes related to data collection and processing or those related to data exchange.

There will be other data providers who will contribute data to the HIE in the future. To ensure the HIE can integrate their data, robust data quality control systems will be needed.

HEDA Data Quality Recommendations

- 1. Compare current data in the HIE with the original data in order to understand the process of data flow, i.e., from data provider to the health information exchange. Determine extent to which the data elements match.
- 2. Create clear documentation of variables in instances where data are transformed or modified. If data are transformed, for example, from address to aggregate area (such as zip code), from continuous to categorical values, or from 30 race/ethnicity categories to 1 race/ethnicity category, it is important to document methods and thoroughly test for data quality.
- 3. Investigate the processes that other data providers have to collect (e.g. their data collection instruments), store, organize, and exchange this race and ethnicity data. For example, health systems and providers may have standardized mechanisms to enter race and ethnicity data into their records, however there is no standard mechanism and no requirement to electronically transfer this information to insurance companies.
- 4. Investigate what data other state agencies and CBOs, might have that could be used to help validate and enhance health equity data elements. For example, self-reported race/ethnicity and real-time address may be known with near-100% accuracy from one data system; these data could be matched to the data stored within the HIE to help establish whether the existing record captures that variable in an accurate way.

Other Considerations

- The HIE is creating a master person identifier (MPI). It is important to understand how systematic biases may occur in this system, i.e. how people are matched for MPI, how matching occurs for individuals who are residentially mobile, and more about the process of matching and the match rates for different at-risk populations within the state.
- The HIE is using a "risk grouper" to differentiate health risks among individuals. To avoid overstating or understating true health risks among varied populations, it is important to have a thorough understanding of how these groupers assess risk in different population groups and across geographies.

Cross-Cutting/Governance Themes

The scale of the Connecticut Information Exchange (Connie) will require a comprehensive and iterative process of quality improvement to insure integrity over time. A governance structure should be developed and tasked with this oversight.

Cross-Cutting/Governance Recommendations

- Institute an iterative and collaborative process to develop specific suggestions, policies, or practices for improving the quality of the health equity data elements within the HIE, communicate those to external and internal partners as needed, and use baseline reporting to monitor these improvements over time.
- 2. Technical assistance may be needed for many of the groups to help them standardize their data mapping/aggregation process so that the HIE better understands what is being contributed and its validity for various health equity data use cases.
- 3. Conduct data testing to understand the validity and potential uses of information collected, especially as they relate to high-priority use cases. Potential examples of data testing approaches that could increase our understanding of the data and lead to recommendations for improvement include:
 - Analyze the current claims data from a public health perspective by creating age adjusted rates and geographic area-level rates to be able to compare differences in the volume, types, or prevalence of claims with other publicly available data that show very large disparities in poor health outcomes across the state (e.g. DPH age-adjusted mortality rates by county or town for conditions such as stroke, birth rates, complications, hospitalizations (e.g. opioid emergency visits, preventable diabetes admissions, asthma hospitalization by town or census tract) and community health surveillance on behaviors and access (e.g. self-reported obesity); census data (for

insurance rates, DSS enrollment). As part of this exercise, the data could be prepared to be stratified by race and gender (to determine if the data source would allow that to be done reliably), and data clustered by the racial/ethnic and socioeconomic characteristics of various zip codes also could be used as a proxy for this.

 Validating residential addresses within the claims dataset, and geocoding these elements to create information below the zip code level. Information would be aggregated into census tract clusters and/or analyzed over a larger time series in order to have a sufficient number of records to examine. For example, the analysis process could obtain data for one town, geocode all addresses to latitude and longitude, and then examine data quality, organize data for aggregation by geography/time period, and examine factors such as potential residential mobility and the distribution of claims/health risks within smaller areas.

Discussion

The challenge of high-quality race and ethnicity data are well-known. A 2004 National Research Council (NRC) report *Eliminating Health Disparities: Measurement and Data Needs*⁴ and the subsequent 2009 report, *Race, Ethnicity, and Language Data: Standardized Healthcare Quality and Improvement*⁵, reported pervasive issues with collection of race and ethnicity data and the necessary operational, technical and scientific, political recommendations to improve the quality of this data. Though a decade has passed since these reports, the COVID-19 pandemic has laid bare these persistent issues of the collection of race and ethnicity data of the limited data categories, with a recent study that demonstrated that few States were collecting data by race and ethnicity.⁶ The significant racial health disparities in Connecticut related to COVID-19 are made more concerning given that 47% of race and ethnicity data was missing for reported COVID-19 cases.^{7, 8} In the context of this heightened need for a comprehensive view of patients during this and future health related disasters, there is an opportunity for Connecticut to push for high quality data on race and ethnicity data and other data elements. With

⁴ National Research Council (US) Panel on DHHS Collection of Race and Ethnic Data, Ver Ploeg M, Perrin E, eds. Eliminating Health Disparities: Measurement and Data Needs. Washington (DC): National Academies Press (US); 2004.

⁵ IOM (Institute of Medicine). 2009. Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement. Washington, DC: The National Academies Press.

⁶ Gross CP, Essien UR, Pasha S, Gross JR, Wang SY, Nunez-Smith M. Racial and Ethnic Disparities in Population-Level Covid-19 Mortality [published online ahead of print, 2020 Aug 4]. J Gen Intern Med. 2020;1-3. doi:10.1007/s11606-020-06081-w

⁷ Putterman, Alex. "Racial Disparities Persist in Connecticut's COVID-19 Outbreak, Prompting Concern about Effects of Potential Second Wave." courant.com, July 13, 2020. <u>https://www.courant.com/coronavirus/hc-news-coronavirus-covid-racial-disparities-20200713-y722eyl3erekvn7qlwvl6a6akm-story.html</u>.

⁸ CT Department of Public Health, COVID -19 Race and Ethnicity Data SummaryApril 28, 2020 <u>https://data.ct.gov/Health-and-Human-Services/CT-DPH-COVID-19-Race-and-Ethnicity-Data-Summary/8pga-qnuw</u>

these stakeholder interviews, we also know that community engagement and participation is critical to embed and sustain equity in Connecticut's health information exchange.

Recommendations for OHS and HIA:

Though the HIE role will be aggregating data across multiple data systems. It is critical that at the foundation that they are actively working with healthcare organizations and public health agencies to understand the process of their data collection and sharing of this data. The HIE could provide funding to regularly train all health care staff about the purpose and collection of these data. The HIE needs to work with racial justice scholars to understand how best to organize and standardize the data within their data systems. This means ensuring not only a unified system of data exchange, but mandating the collection of accurate information on self-reported race, ethnicity, preferred language, geography, and other factors. Self-reported health-related social needs (such as housing, food, transportation) and community assets that provide critical services to those with specific needs can also be incorporated into the system.

- 1) Set standards for data collection and roll-up of granular race and ethnicity data. This includes leveraging the work accomplished by the State Innovation Model. For example, in 2018, Health Equity Solutions submitted a report detailing recommendations for granular race and ethnicity data collection.⁹ Results of the HEDA team's stakeholder outreach (Appendix A) confirm the wide variety of race, ethnicity, and insurance status data are being captured across Connecticut state agencies and community-based organizations. Although OMB-5 categories are universally being collected, to identify health disparities of specific populations, standardizing granular fields for race, ethnicity and insurance type would build the foundation for equity in Connecticut. To address the low levels of data completeness in the APCD (Appendix B), further requirements are needed that mandate the inclusion of race and ethnicity data in transmissions of claims and EHR based data. This would ensure that race and ethnicity data that are being collected at the provider level, per meaningful use requirements, are also being transmitted to insurance companies and the APCD.
- 2) Set policies that require health systems, organizations, and agencies to collect and report granular REL data in standardized mechanisms through state legislation. This includes expanding uniform collection and reporting of detailed race, ethnicity, and language data, as was proposed in Connecticut through legislation and debated, but not moved in the Public Health Committee. Leveraging Community Benefit and/or the Certificate of Need processes to require hospitals to collect health equity data elements (race, ethnicity, language data and insurance status) as a part of evaluation and mandated reporting criteria would provide another mechanism to improve data quality and completeness. Building on the lessons learned through the SIM

⁹ Health Equity Solutions, Recommendations for Granular Race & Ethnicity Data Collection, October 2018. Report prepared for the SIM Program Staff, Connecticut Office of Health Strategy.

Community and Clinical Integration Program (CCIP)¹⁰, requiring the expansion of data collection standards as a part of state contracting would provide another mechanism for standardizing data collection and reporting. It will also be crucial for OHS to engage in further investigations of the specific legal and infrastructure challenges facing potential adopters in complying with changes to their current data collection and reporting. In particular, state agencies may require additional legislation to resolve these challenges.

- 3) Invest in the creation of a Health Equity Data Officer position and team and the infrastructure and resources needed for adequate staffing and operations. An Officer position with the support of dedicated staff is needed to expand access, information, and resources to help remedy the low quality and level of health equity data that is currently available. Additional questions for consideration include: where might the addition of an equity-specific data monitor or officer add value to a system, for example the Health Information Alliance, the Department of Public Health or the Office of Policy and Management? What additional resources such as staff or analytics do equity data officers require to optimize the collection, reporting and use of health equity data elements? How might a Health Equity Data Officer and/or analytics team support state leaders, academic health centers, and community providers in having ready access to current institutional-level data on race and ethnicity about their own organization and their surrounding community? How might an Equity Data Officer facilitate data analytic capacities and collaborations across different agencies? Based on similar projects, a team would need to be convened to develop the structure of this position and staff, the operational flow, and to determine where this position would be housed.
- 4) Perform an equity audit to assess the ways that patients and consumers are being engaged. Patient and consumer participation needs to be empowered and central to embedding equity within the health information exchange.¹¹ At the institutional level, there are existing roles, such as patient advisory councils in hospitals or community advisory stakeholders in academia or consumer advisory councils at state agencies, which provide input into institutional processes in a way that advances equity values and enables communities to co-build a participatory approach to REL data collection and use. What is the membership of these councils? How are these individuals selected and then involved in the data lifecycle process? How much power do these individuals and communities have in decisions about prioritization of funding, access, transparency and accountability regarding data? Do these individuals have

¹⁰ Connecticut State Innovation Model (SIM) Report of the Practice Transformation Taskforce on Community and Clinical Integration Program Standards for Advanced Networks and Federally Qualified Health Centers. <u>https://portal.ct.gov/-/media/OHS/SIM/PracticeTransformationTaskForce/Resources/Final-Report-of-the-Practice-Transformation-Task-Force-on-CCIP.pdf?la=en</u>

¹¹ Hawn Nelson, A., Jenkins, D., Zanti, S., Katz, M., Berkowitz, E., et al. (2020). A Toolkit for Centering Racial Equity Throughout Data Integration. Actionable Intelligence for Social Policy, University of Pennsylvania.

an empowered decision-making role in how data are collected and used? Does the HIA have a consumer or community advisory board or plans to develop one in the near future?

5) Form an interdisciplinary team inclusive of social scientists (e.g. critical race scholars) and data ethics and informatics experts to ensure that decisions pertaining to the creation of future standards for the collection, sharing, exchange and use of data in the HIE are assessed with a health equity lens. Ensuring health equity is embedded throughout the data life cycle of Connecticut's HIE will call for continued efforts to assess, monitor and course-correct as Connie continues to develop and sign on trusted partners. It would serve OHS and the HIA to have access to a team of interdisciplinary social scientists who can provide expertise on advancing equity in aspects of data collection and data sharing.

The HEDA team's data and policy recommendations described above serve as the beginning dialogue to ensure equity is considered throughout the data life cycle. As the health information exchange continues to develop, it will be important to consistently conduct data equity audits for potential unintended consequences.

Appendix A

The following tables summarize the race and ethnicity data elements (Table 1) and insurance data elements (Table 2) currently being collected by the following agencies and organizations in Connecticut. The dotted line in Table 1 represents a demarcation between race fields and ethnicity fields being collected.

DPH Minimum standard	DPH Ideal Standard	DSS	DHMAS	ннс
American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White	American Indian or Alaska Native; specify tribal affiliation: Asian Asian Indian Korean Chinese Taiwanese	Black or African American Al affiliation: American Indian or Alaska Native Hispanic or Latino/a Asian Indian Chinese Filipino	American Indian/Native Alaskan Asian Black/African American Native Hawaiian/Other Pacific Islander White/Caucasian Other Unknown	White (European, Middle Eastern, Arab, North African) Black/African American (African, African American, Haitian, Jamaican, Dominican, West Indian) American Indian/Alaskan Native
Hispanic or Latino Not Hispanic or Latino (OMB 1997)	Filipino Vietnamese Japanese Other Asian; specify: Black or African American Native Hawaiian or Other Pacific Islander White	Japanese Korean Vietnamese Other Asian Native Hawaiian Samoan Guamanian or Chamorro	Unknown	Asian (Chinese, Vietnamese, Cambodian, Asian Indian, other) Native Hawaiian/Other Pacific Islander Other:
DOH	Other race; specify:	Other Pacific Islander		
OMB 1997 + Client Doesn't Know Client Refused Data Not Collected	Hispanic or Latino Cuban Mexican Puerto Rican South or Central American Other Hispanic/Latin culture or origin, regardless of race; specify: Not Hispanic or Latino	Mexican Mexican-American Chicano/a Cuban Puerto Rican Other Hispanic, Latino/a or Spanish *Renewal of Eligibility form		Puerto Rican Mexican Cuban Dominican Central American (Salvadorian, Honduran, Guatemalan, other) South American (Colombian, Ecuadorian, Peruvian, other) Other Hispanic/Latino: *Breastfeeding Heritage & Pride program intake

Table 1: Summary of race and ethnicity data fields collected from stakeholder outreach

Table 2: Summary of insurance data fields collected from stakeholder outreach:

DHMAS	DOH	DPH	TVCCA	ННС
No health insurance Other private insurance Medicare Champus Medicaid Husky C HMO (including Managed Medicaid) GA-SAGA ATR-Access to Recovery Self Pay Medicaid LIA Husky D Medicare Part A Medicare Part B Money Follows The Person (MFP) Nursing Home Waiver Medicaid BHH Medicaid- Husky A Medicaid BHH - Waiver Other Unknown	• Yes • No • Client Doesn't Know • Client Refused *(Statewide Coordinated Access Network Intake)	Not included in either minimum or ideal standard sociodemographic data collection	Direct purchase Employment Military Medicaid Medicare CHIP State insurance adult, none, unknown, unreported	Program dependent. Breastfeeding program does not collect

Appendix B

The following data were prepared by UCONN AIMS based on a limited data set of the Connecticut All-Payer Claims Database. The limited data set contained approximately 1.4 million unique individuals with commercial insurance. This data was released by OHS to UCONN AIMS and shared with the HEDA team.

Year	Primary Race	Primary Race Secondary Race Primary Ethnicity		Secondary Ethnicity	
OVERALL	8.77%	5.63%	10.44%	10.44%	
2012	8.33%	8.14%	10.32%	10.32%	
2013	8.16%	7.19%	10.28%	10.28%	
2014	8.64%	6.38%	11.18%	11.18%	
2015	8.76%	5.12%	10.85%	10.85%	
2016	8.90%	4.30%	10.83%	10.83%	
2017	9.26%	3.57%	9.84%	9.84%	
2018	9.55%	4.06%	9.58%	9.58%	

Table 1: Race & Ethnicity data completeness

Table 2: Race and Ethnicity Unique Counts

	Numerator				Denominator
Year	Primary Race	Secondary Race	Primary Ethnicity	Secondary Ethnicity	Total Unique Individuals
2012	123,549	120,638	152,950	152,950	1,482,510
2013	121,742	107,406	153,487	153,487	1,492,811
2014	131,213	96,852	169,629	169,629	1,517,815
2015	125,321	73,197	155,125	155,125	1,429,826
2016	120,109	58,085	146,160	146,160	1,349,848
2017	128,399	49,439	136,355	136,355	1,386,057
2018	111,625	47,515	112,036	112,036	1,169,079

Source: CT APCD Limited Data Set (2012 – 2018). Released by CT OHS to UCONN AIMS. Commercial Population Analysis by: UCONN AIMS (2020).

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